



Regional special care nursery environments: navigating the role of mother

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Abstract

Premature birth presents challenges for most mothers assuming a parenting role with their infant. Living in rural and regional areas provides additional hardship due to isolation, distances and limited support services. The predominant focus of research in the area of premature birth has been on the survival of infants. There has been limited investigation of the experiences of women with infants in special care nurseries (SCNs), in regional Australia. The ways in which mothers 'navigate their way', physically and emotionally, in SCN environments was the focus of this study.

Using a qualitative interpretive design data were collected through in-depth interviews with mothers and analysed thematically. Women related a dislocation in their lives as a result of their infant's hospitalisation. The nursery space and the various ways space was used to marginalise or sanction mothers was revealed and resulted in women adopting conflicting roles throughout this time. These findings provide direction for developing more supportive environments for parents relying on SCNs for the care of their infant.

This study provides new insight into the experiences of women and their environmental sensitivity within SCN settings. Findings will increase regional midwives' understanding of mothers' interpretations of the neonatal nursery environment. Insights into maternal perspectives will assist in the provision of better family-centred care and improved outcomes for the vulnerable families of premature infants.

Introduction

Premature birth compounds the stress associated with the transition to parenthood.¹ The birth of a premature infant is often sudden, unexpected and associated with an acutely ill infant, thus representing a major crisis for mothers², which impacts in many ways. Most premature infants are born between 32 and 36 weeks gestation; premature births account for 6–10% of all births in developed countries³ and in 2003–2004, 7.8% of all births in Victoria were premature⁴ with nearly one quarter of these from rural regions.

Premature infants from regional and rural areas are generally transferred to tertiary centres if under 32–34 weeks gestation, due to possible intensive care requirements.⁵ These specialist services are currently only available at larger hospitals in metropolitan areas. Transfers result in separation of mothers from family and dislocation from familiar supports. In Victoria, transfers to neonatal intensive care units (NICU) may result in parents travelling several hundred kilometres from their home. Understandably, distance has been identified as a stressor in some international NICU studies⁶ but not specifically in a rural context and there is scant exploration of this topic in relation to mothers with hospitalised premature infants. Currently, distance to health services is measured in kilometres but due to varying quality of roads and driving conditions in rural areas, Australian Institute of Health and Welfare⁷ recommends travel time may be more relevant than distance.

Neonatal care has developed progressively since the late 1800s with developments in technological support that facilitated the survival of infants of lower gestation to survive.⁸ Three periods in this development have been noted: the 'hands off' period in the first half of the twentieth century, followed by the 'heroic' period from 1950–1970, and the third period is referred to as 'experienced' from 1970–2000.⁹ Neonatal care became increasingly institutionalised in the first two phases with the use of incubators (isolettes) to improve survival rates and subsequent exclusion of parents who were identified as possible sources of infection.¹⁰ It was not until the 'experienced' phase that accompanying

changes to obstetric practice supported natural childbirth²; these changes included a greater acknowledgement of the family and its psychological wellbeing which remains evident in most units and is promoted as family centred care.¹¹ Despite the large investment in improving outcomes for neonates, there has been minimal investigation into the experiences of the parents whose infant is born prematurely and hospitalised for a prolonged period.

In Victoria, nurseries are categorised into three levels: Level 1 care, providing care for well infants at the mothers' bedsides; Level II care or Special Care Nurseries (SCNs), providing intermediate care with nursery admission, investigation and monitoring; and Level III care or NICUs, offering life support with high dependency care including assisted mechanical ventilation, intravenous nutrition and specialised neonatal staff.⁵ Regional SCNs may be classified as high or low dependency level II, providing care for infants over 32 weeks gestation.^{5,12} Depending on classification, level II SCNs deliver a high level of acute care, which is decreased as infants become more stable.

With the need for vigilant surveillance of infants, staff are constantly present in neonatal nurseries which are often designed for accessible observation from all vantage points as a priority. A consequence of this design is little privacy for mothers. The analogy of a 'fishbowl' used by Klaus et al.², in relation to lack of privacy and the negative effect on attachment, matched mothers' interpretations in some studies¹³; likewise Boyd¹⁴ described the difficulty of having to 'parent in public' (p. 83). Thus, the nursery can be considered an environment of 'exposure': the infant is exposed for required observation and monitoring; the mother is exposed in her vulnerable state¹⁵ and the neonatal staff are exposed to possible scrutiny by the mother as she often has little to do but 'sit and watch'.¹⁶ Despite the differences in NICU and SCN environments, similarities have been identified in parental responses with both settings interpreted as medicalised and task-orientated areas.^{17,18} This study explored the experiences of eight women with hospitalised premature infants in regional SCNs revealed day-to-day difficulties. Predominant themes interpreted from the data were women's dislocated lives, staff interactions, sense of identity and space. The content of this paper will focus on the women's accounts of how the spatial arrangements of the nursery impacted on them.

Method

The study aimed to elucidate experiences of a group of women living in regional or rural Western Victoria who gave birth prematurely, using qualitative interpretive description.¹⁹ Eight women agreed to participate in this study and shared their stories of regional SCNs. Women who had given birth within the previous 12 months and had infants who had been hospitalised for at least ten days were invited, in individual interviews, to comment on their experiences. Women responded to fliers at Maternal and Child Health Nurse Centres, or advertisements placed in the newsletters and websites of special interest groups. Mothers with specific welfare or social issues (such as drug addiction) were excluded from this study, as they are a particularly vulnerable population. Informed consent was obtained prior to interviews.

Participants were white, middle-class and only two were multiparous. Their ages ranged from 26–40 years of age. Most resided on small acreages in peaceful rural settings, some distance from their regional hospital, although one participant lived in a town and another on a large rural property. Six mothers underwent emergency Caesareans for complicated pregnancies, including antepartum haemorrhage and pre-eclampsia. Two participants suffered from postnatal depression. Infants' gestational ages ranged from 27 to 35 weeks with six infants spending time in a tertiary NICU prior to transfer to the regional SCN.

The methodology was underpinned and complemented by feminist principles to explore the complexities of mothers' roles within this specific setting. Feminist reconstruction of maternal roles in recent times provided a suitable framework for this study. Invisibility of women in many arenas has long been acknowledged by feminists²⁰ and more specifically by researchers in neonatal literature.²¹

Data were collected by in-depth semi-structured interviews which were audiotaped and subsequently transcribed by one of the researchers (KK). Thematic analysis²² through inductive emergence and extraction was undertaken to identify common patterns or differences within the data. Clearly



identifiable themes overlapped and entwined closely with each other, forming a pattern dominated by participants' struggle for control as well as their search for location and identity within the SCN.

Findings

Women's stories revealed a complex set of concerns that the space of the nursery presented which impacted in many ways: physical restrictions and 'confinement'; mother-infant relationship; privacy; staff-parent relationships; and social interaction with other patients and visitors. Physical proximity to their infant was challenging with issues of separation, distance and family responsibilities, but was also difficult within SCN boundaries. Various difficulties were encountered by women in the confined space shared with a socially diverse group of individuals—staff, families and visitors. Spatial aspects of the SCN environment required major adjustment and were a significant influence on women during their transition to becoming a mother. The theme of space was explored under the sub themes of location and exposure. Women's comments are used to illustrate the findings and are italicised in the text.

Location: *Such a small, confined space*

The nursery environment and its effect were prominent throughout women's dialogues. Their perception of the physical space indicated they found SCN a cramped area full of activity, which they described as noisy and disturbing. Space limitations were evident with descriptions of cots being placed *cheek to jowl* resulting in women needing to *squeeze in and out* between them. The apparent full capacity of these nurseries, constant alarming of monitors, disruptive visitors and 'busy' neonatal staff, intensified difficulties for participants trying to access their infants. This confined space in an acute area of the hospital created a tension for women wanting to remain with their infant as much as possible but also *trying to keep out of the way* during emergency admissions.

Staff used spaces within the nursery to restrict or control women's activities; accounts of not being 'allowed' to remove their own breast milk from the fridge or handle their infant in the isolette exemplified the disempowerment experienced by these women. Most resisted this authority, albeit in different ways: physical withdrawal, where some took their infants out to other areas they found *less medical*, or adopting nursing roles and *doing all the care* for their infant as they developed trust in their own abilities. The close proximity to staff resulted in women being unable to *relax* within the medicalised environment in which they felt the need to 'prove' their capabilities as a mother who was coping, *I just didn't want them to see I was falling apart*.

Infants transferred from isolettes to small portable cots were reportedly placed indiscriminately in open areas of SCN, *in the middle of nowhere*, consequently preventing participants creating their own space both for themselves and their infant. Staff often shifted cots around and the changed locations were unsettling and disruptive for women who craved stability in a time of dislocation. The lack of allocated space resulted in women not being able to have their *own space*. Most women described the need to personalise a space for their infant with blankets or toys to reinforce the feeling of their infant being their own, but related difficulties in achieving this with the lack of allocated space, which heightened their sense of displacement. Meaningful attempts to personalise or change existing spaces, for example providing individual trays for their own breast milk, were often devalued. In some instances, personal items on infants' cots were removed by staff without explanation. One participant explained, *you're very much stepping on their [staff's] territory*.

Exposure: *Nowhere to go*

Most participants lived 'out of town' and their rural lifestyle was an intrinsic part of their identity. The contrast of environments—the quiet rural home setting compared to a densely populated nursery was noted by participants as an added stress. Geographical distance from home, *the difficulties of travel* and travelling time heightened women's sense of abandoning their infants, *I could only get in once a day*. Women recovering from surgical births were mostly dependent on others for transportation, however one participant drove the daily two hour return trip herself due to limited family support and *no choice*. In some ways, their geographical dislocation was a direct reflection of the fragmentation of emotions.

Limitations with space and the need to share social space at a vulnerable time, was seen as especially difficult.

Reports of perceived scrutiny by staff or visitors and exposure to confronting events such as infant resuscitation, *public events that aren't yours*, indicated participants' discomfort with the environment and the difficulty they experienced sharing such a confined space with others. Withdrawing from the nursery helped minimise emotional exposure, *I just don't like it that everyone's looking at me, and the baby...especially on days that I just wanted to cry*, and allowed women some privacy. Most participants reiterated the need to *get out* or *retreat* but were frustrated at having *nowhere to go*, as other areas near SCN such as lounge rooms were often occupied. Only one participant living in a town, *five minutes away – we had nothing to complain about*, was able to go home between feeds *just to get away from the nursery*. However, this was an impractical or undesirable option for those participants living in outlying areas. Women with other children reported feeling *torn* between their two 'families', the compelling need to be with their infant in SCN competing with family responsibilities at their home some distance away.

The socio-economic mix of families seemed particularly complex and intense within a restricted, busy area, where some participants described exposure to families outside their normal social realm. The behaviour and characteristics of some disadvantaged families were deemed undesirable and possibly detrimental by participants to their own and their infant's wellbeing. Some visitors to SCN were described as *disgusting* and *unhygienic* with *kids that were coughing and spluttering* [all over the infants] and clearly perceived as a risk to *vulnerable, fragile* infants. Lack of visitor regulation by staff, allowed some visitors to *peer at all the babies* [in SCN] or *take over the lounge*, therefore limiting other 'retreat' areas for women. Space allocated to all families, such as lounge rooms, became space for only some, due to the reluctance to share social space with others seen as less desirable.

Lack of privacy, a feeling of surveillance and a reported broad socio-economic blend of families resulted in women wanting to take their infants beyond the nursery space. Women perceived less clinical areas within the hospital as more home-like and felt a greater sense of ownership and responsibility of their infants. Clearly, the use of different spaces allowed women a refuge from the public gaze of the SCN, as well as creation of their own private space and a sense of freedom. *Getting out* and having an area of their own was closely linked to feeling the infant belonged to them and thus reflected feeling like a mother.

Discussion

Women in this study described emotional responses to their infant's premature birth and hospitalisation that included shock, grief, anxiety and guilt, responses consistent with findings from other studies of nursery parents.^{23,24} However, geographical distance from home and difficulty 'navigating' SCN space intensified participants' feelings of dislocation and increased the sense of having 'two lives', one in SCN and one at home. They traversed between two nurseries – a busy and controlled one in hospital and a silent, empty one at home. Participants were away from the familiarity of their home for most of the day, spending their time in an intense, medicalised environment, which they attempted to make more home-like. Space was used by staff to control the location of infants and direct caretaking by mothers and activities such as cot positioning by SCN staff ameliorated women's sense of their own territory.

Situational conditions, such as distance and limited support, as well as family factors have been identified in other studies as impacting on women's perceptions of neonatal nurseries⁶, but generally effects of distance are under reported. The regional focus of this research highlighted issues of environmental sensitivity to SCN settings as well as the impact of geographical distances, both of which are under represented in published literature. Within the limited field of research specific to SCNs there are no published studies exploring SCN experiences of women related to their urban or rural location. A larger study of mothers in SCNs making rural-urban comparisons may identify if the findings reported here are particular to rural women or more generalised and similar for all women.



Shared space

Within a regional context, nearly all participants resided in quiet rural areas, valuing both space and privacy, characteristics not found in SCNs. Findings indicated a tension between the desire and ensuing difficulty for women to make their infant's temporary home feel like their own home. Space has complex definitions but findings from this study reinforce the notion of behaviour and space being mutually dependent²⁵ with accounts of SCN environments demonstrating how spaces are used to regulate social interaction.²⁶ Descriptions indicated characteristics of a clearly marked territory enclosed within the authoritarian boundary of a hospital and clearly revealed 'spatial forms of social control'²⁷ with staff controlling many activities. This inequality of power where a confined space highlighted the dominance of nursery staff has parallels with other neonatal investigations.¹⁵ High levels of visibility and audibility aggravated women's sense of scrutiny and inhibited their parenting roles. Space restrictions, the impact of crowding combined with the prolonged maintenance of social roles within a hospital added to women's difficulty of maternal role adjustment.

Environmental sensitivity through different perspectives was evident in women's accounts. At a time of transition to becoming a mother, women needed time and space to adjust to the new role, yet the establishment of personal space was difficult and women needed to negotiate sharing space with others. Women expended physical and emotional energy in these negotiations, a finding described by Altman²⁶ whenever privacy is sought. Lack of privacy is particularly pertinent in a regional context with smaller populations and increased chance of contact outside the hospital environment. Social proximity lends itself to possible future encounters with families from the SCN where confidential information may have been informally gathered. Privacy and confidentiality issues in rural and regional areas have been discussed by others²⁸ but usually from the perspective of health providers rather than health consumers. Further insights into regional family views related to privacy would be valuable in terms of providing care which meets their needs, as families from a wide range of socio-economic groups are required to share nursery space and spend time in close proximity. The juxtaposition of different individuals in these SCNs was challenging for women in this study.

While other neonatal investigations have alluded to power struggles and staff interaction^{15,16} there is a paucity of literature relating to the intersection of space and power. The psychosocial and cultural nuances described by women in this study indicate 'spatial challenges' for all individuals within nursery environments, which need to be addressed by organisational changes, incorporating input from parents and commitment by neonatal staff.

Implications for future research and practice

These findings provide direction for further research and clinical practice development in SCNs. There are clearly opportunities for the spatial arrangements of SCNs in regional settings to be reconsidered to reflect family requirements rather than staff convenience. Educational and support for staff in SCNs is needed to facilitate changes to practice, develop an increased awareness of nursery culture and consider utilisation of space. Few studies specifically explore the transition from NICUs in metropolitan tertiary centres to regional SCNs, yet there are evidently challenges for families undergoing this transition. While representative of improvement in their infant's physiological state, regional transfers represent another 'space' to which mothers must adjust. Increased pressure on NICU beds is likely to result in smaller infants being transferred to regional areas with resultant longer stays.

Social issues, such as gender and class divisions and their relationship to space, have received little attention in published literature. Further research exploring the experiences of socially disadvantaged groups may reveal differences in perceptions among more diverse population groups. The emerging findings on the behavioural impact and organisational dynamics of the nursery environment demonstrate enormous potential for the convergence of geographical and nursing research, which is currently lacking.

Conclusion

The disruption, trauma and dislocation to eight regional women's lives as a result of premature birth were intensified by spatial and social issues within regional SCN environments which disempowered them not only as mothers but also individuals. Validating women's interpretation of SCNs will assist in the provision of individualised care with a family-centred approach.

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Presenter

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